AUTISM: WHERE ARE WE NOW?

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What have you heard about autism?

OR

FACT

Facts & Figures . . .

- Estimated over 1.8 million cases of autism in the US
- New case is diagnosed every 20 minutes
- 1 in 68 children currently being diagnosed (CDC, 2014)
  - 1 in 50 via parent report in 2013
- Boys are 5x more likely than girls
- Autism is the fastest growing developmental disability in the US
- Costs 126 billion annually in the US
- The journal Pediatrics suggests that an autism diagnosis brings an annual cost of $17,081 per child
- 2.3 million dollars to care for an individual with autism over their life span

What does autism look like?

Stephen Shore once said:

"If you've met one person with autism, you've met one person with autism."

Jade stacking blocks

Response to Name

No Myths

Adult with autism

Repetetive Behaviors

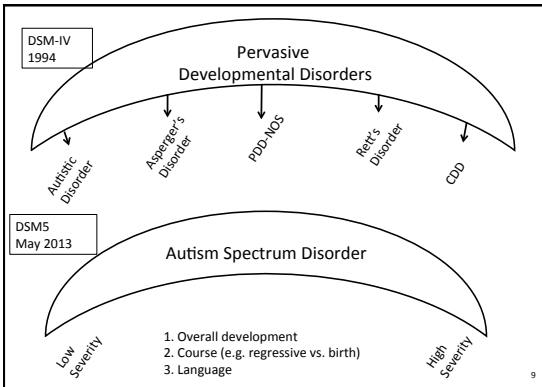
What is the DSM?

- The Diagnostic and Statistical Manual of Mental Disorders, is used by clinicians and psychiatrists to diagnose psychiatric illnesses. The DSM is published by the American Psychiatric Association and covers all categories of *mental health disorders* for both adults and children. The manual is non-theoretical and focused mostly on **describing symptoms** as well as **statistics** concerning which gender is most affected by the illness, the typical age of onset, the effects of treatment, and common treatment approaches.

History of Autism in the DSM

- The DSM-I was originally released in 1952
  - autistic-like symptoms were diagnosed under the schizophrenic reaction, childhood type label
- DSM-II in 1968
  - autism was not included as a separate diagnostic category
  - "the condition may be manifested by autistic, atypical and withdrawn behavior."
  - Children exhibiting these behaviors were diagnosed as *schizophrenic*, childhood type.

- DSM-III in 1980
  - inclusion of autism as a separate diagnostic category: *infantile autism*.
  - due to some controversy surrounding the descriptor "infantile", this category was changed to *autistic disorder* in 1987.
- DSM-IV in 1994
  - over arching category of *pervasive developmental disorders* was created with several subtypes included under that designation



Why the changes to the DSM?

- Currently, good at reliably diagnosing "spectrum" from typical development
- NOT so good at distinctions within the disorder
  - Inconsistent over time
  - Vary across sites
  - Often associated with different things (ex. language and cognition as opposed to their "autism")

Autism Symptoms Checklist		
A. Six or more symptoms from (1), (2), or (3)	Yes	No
(1) Impairment in social interaction, as indicated by AT LEAST TWO of the following:		
a. Marked impairment in the use of multiple nonverbal behaviors (such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction	☐	☐
b. Failure to develop peer relationships appropriate to developmental level	☐	☐
c. Stereotyped and repetitive use of language or idiosyncratic language	☐	☐
d. Does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace	☐	☐
e. Lack of social or emotional reciprocity	☐	☐
(2) Impairments in communication as indicated by AT LEAST ONE of the following:		
a. Delay in, or total lack of, the development of spoken language (without an attempt to use alternative modes of communication such as gestures or mime)	☐	☐
b. In individuals with adequate speech - marked impairment in the ability to initiate or sustain a conversation with others	☐	☐
c. Stereotyped and repetitive use of language or idiosyncratic language	☐	☐
d. Does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace	☐	☐
(3) Restricted repetitive and stereotyped patterns of behavior,interests, and activities, as indicated by AT LEAST ONE of the following:		
a. Preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus	☐	☐
b. Adherence to routines or ritualistic patterns of verbal or nonverbal behavior	☐	☐
c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)	☐	☐
d. Persistent preoccupation with parts of objects	☐	☐
B. Delays or abnormal functioning in AT LEAST ONE of the following areas, with onset prior to age 3 years:		
(1) Social interaction	☐	☐
(2) Language as used in social communication	☐	☐
(3) Symbolic or imaginative play	☐	☐
C. The symptoms are not better accounted for by:		
(1) Rett's Disorder		
(2) Childhood Disintegrative Disorder		
*This checklist has been adapted from the DSM-IV diagnostic criteria for Autistic Disorder		

Changes to New DSM V

- Three domains become two:
  - Social/communication deficits
  - Restrictive interests and repetitive behaviors
- Must meet following 4 criteria:

A. Persistent deficits in social communication

B. Restricted, repetitive interests or behavior

C. Symptoms must be present from early childhood

D. Symptoms together must limit and impair everyday functioning

299.00
Autistic Disorder

Proposed Revision | Rationale | Severity | DSM-IV

Revised January 26, 2011

Severity Level for ASD	Social Communication	Restricted interests & repetitive behaviors
Level 3 'Requiring very substantial support'	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others.	Preoccupations, fixated rituals and/or repetitive behaviors markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect from fixated interest or returns to it quickly.
Level 2 'Requiring substantial support'	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others.	RRBs and/or preoccupations or fixated interests appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress or frustration is apparent when RRB's are interrupted; difficult to redirect from fixated interest.
Level 1 'Requiring support'	Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions.	Rituals and repetitive behaviors (RRB's) cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRB's or to be redirected from fixated interest.

DSM-V Severity Levels – Level 3
"Requiring **very substantial** support"

Social Communication

- Severe deficits in verbal and nonverbal social communication skills that cause severe impairments in functioning. Limited social interactions and minimal response to social cues.

Repetitive/Restrictive Interests

- Preoccupations, fixated rituals, and/or repetitive behaviors markedly interfere with functioning in all spheres. Marked distress when rituals are disrupted.

DSM-V Severity Levels – Level 2
"Requiring **substantial** support"

Social Communication

- Marked deficits in verbal and nonverbal social communication skills, impairments apparent even with supports in place, limited initiation an reduced response

Repetitive/Restrictive Interests

- Rituals appear frequently enough to be obvious to casual observers and interfere with functioning. Distress noted if interrupted, difficult to redirect

DSM-V Severity Levels – Level 1
"Requiring support"

Social Communication

- Without supports in place, deficits in SC cause noticeable impairments. Difficulty initiating social interactions, atypical responses, decreased interest in social interactions.

Repetitive/Restrictive Interests

- Rituals cause significant interference with functioning in one or more contexts. Resist attempts to interrupt rituals or be redirected.

Important to Note:

- The National Institutes of Mental Health announced that **they will no longer be using the new DSM5** definitions and diagnosis for researchers anymore. Why did this happen? How might this affect the value of the DSM5?
  - New Research Domain Criteria
  - "Develop, for research purposes, new ways of classifying mental disorders based on dimensions of observable behavior and neurobiological measures."
  - http://www.nimh.nih.gov/research-priorities/rdoc/nimh-research-domain-criteria-rdoc.shtml

Definition:

The million dollar question!

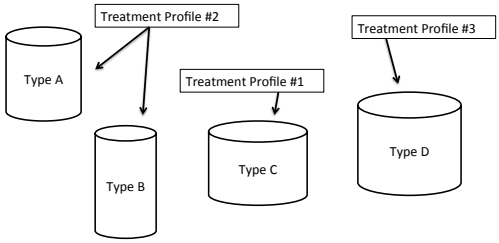
WHAT CAUSES AUTISM?

Some Theories

- Genetics
- Brain Development
- Medical Conditions
  - Fragile X
  - phenylketonuria [PKU]
  - micro/macrocephaly
  - Epilepsy
- Babies –
  - EEGs
  - eye contact
  - motion
- Environmental
  - Pollution!
  - Paternal age
  - Prematurity
  - Flu/Fevers in Mother
  - Folic Acid
  - Food supply
- [illegible]ines

What do many researchers/scientists think?

Autism Phenotypes



Autism & Education

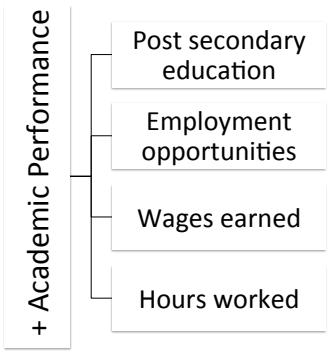
- Based on statistics from the U.S. Department of Education and other governmental agencies, autism is growing at a rate of 10-17% per year. At these rates, it is estimated that the prevalence of autism could reach four million Americans in the next decade.
- 56% of students with autism finish H.S.
- 1 in 3 adults with an ASD lack professional experience
- Where are children with autism placed in public schools?

  . . . . . EVERYWHERE!!!!!!!!

Looking at the numbers. . .

- College enrollment for individuals with autism is the third lowest when compared to other disability categories
  - Ranked #1 in STEM participation rates, however!
    - Baron-Cohen et al., 2007
- Estimated that only 37% of young adults with ASD are employed
  - Part time
  - Majority receive no benefits
- ASD + ID *more* likely to be employed than those without ID!

(Fleury et al., 2014; Taylor & Seltzer, 2011)



Fleury et al., 2014

Strengths that support academics:

- Kunda & Goel, 2011: Enhanced visual processing
- Happé & Frith, 2006: Detail oriented (as opposed to "big picture")
- Wei et al, 2012: Interest in computers and technology
- Kluth, 2003: Topic mastery
- Chiang & Lin, 2007: Reading decoding

Struggles with academics:

- Williams, Goldstein & Minshew, 2006:
  - Limited theory of mind impacts writing quality
  - Motor difficulties impact writing abilities
- Chiang & Lin, 2007:
  - Decreased rate of reading improvement
  - Difficulties with reading comprehension
  - Difficulty with word, story and sentence recall
- Cashin & Barker 2009:
  - May process auditory or linguistic information at a slower rate than their peers

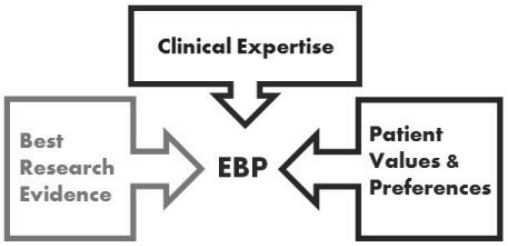
Come on a journey with me!

Flying Penguins

- Can penguins fly?

- What is pseudoscience?
  - A collection of beliefs or practices mistakenly regarded as being based on scientific method.
  - Lacks supporting evidence
  - Cannot be reliably tested

What does the science say?



EBP = Evidence Based Practice

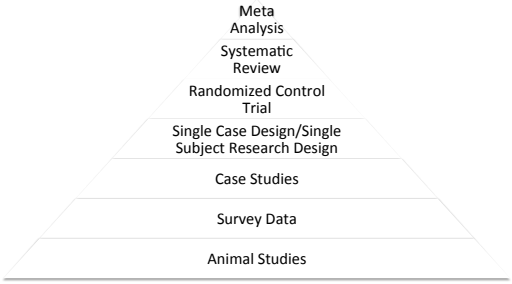
Evidence Based Practice

- The most common definition of EBP is taken from Dr. David Sackett. EBP is "the conscientious, explicit and judicious use of current best evidence in making decisions about the care of the individual patient. It means integrating *individual clinical expertise* with the *best available external clinical evidence* from **systematic research**." (Sackett D, 1996)
- EBP is the integration of
  - clinical expertise,
  - patient values,
  - and the best research evidence!
    (Sackett D, 2002)

American Speech Language and Hearing Association

http://www.ncepmaps.org/Autism-Spectrum-Disorders-Evidence-Map.php

Types of Evidence



Examples of a Systematic Reviews:

National Autism Council

- National Standards Report (2009)
- This report provides comprehensive information about the level of scientific evidence that exists in support of the many educational and behavioral treatments currently available for individuals with Autism Spectrum Disorders (ASD).

National Professional Development Center on ASD

- Evidence-Based Practices for Children, Youth, and Young Adults with ASD (2014)
- "The increased prevalence of ASD has intensified the demand for effective educational and therapeutic services, and intervention science is now providing evidence about which practices are effective."

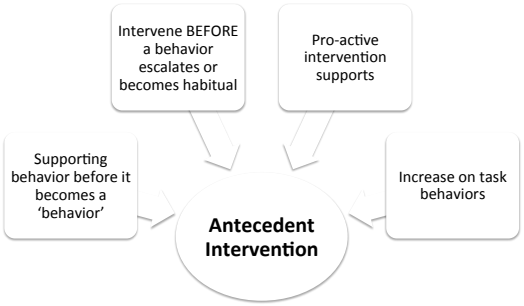
NPDC & NAS Comparison Chart

Overlap Between Evidence-Based Practices Identified by the National Professional Development Center (NPDC) on ASD and the National Standards Project (NSP)

Evidence-Based Practices Identified by the National Professional Development Center (NPDC) on ASD	Established Treatments Identified by the National Standards Project (NSP)										
	Antecedent Package	Behavioral Package	Story-based Intervention Package	Modeling	Naturalistic Teaching Strategies	Peer Training Package	Pivotal Response Treatment	Scheduling	Self-Management	Comprehensive Behavioral Treatment for Young Children	Joint Attention Intervention
Prompting	X			X						The NPDC on ASD did not review comprehensive treatment models. Components of The Comprehensive Behavioral Treatment of Young Children overlap with many NPDC-identified practices.	The NPDC on ASD considers joint attention to be an outcome rather than an intervention. Components of joint attention interventions overlap with many NPDC-identified practices.
Antecedent-Based Intervention	X										
Time delay	X										
Reinforcement		X									
Task analysis		X									
Discrete Trial Training		X									
Functional Behavior Analysis		X									
Functional Communication Training		X									
Response Interruption/Redirection		X									
Differential Reinforcement		X									
Social Narratives			X								
Video Modeling				X							
Naturalistic Interventions					X						
Peer Mediated Intervention						X					
Pivotal Response Training							X				
Visual Supports								X			
Structured Work Systems								X			
Self-Management									X		
Parent Implemented Intervention	The NSP did not consider parent-implemented intervention as a category of evidence-based practice. However, 24 of the studies reviewed by the NSP under other intervention categories involve parents implementing the intervention.										
Social Skills Training Groups	Social Skills Training Groups (Social Skills Package) was identified as an emerging practice by the NSP.										
Speech Generating Devices	Speech Generating Devices (Augmentative and Alternative Communication Device) was identified as an emerging practice by the NSP.										
Computer Aided Instruction	Computer Aided Instruction (Technology-based Treatment) was identified as an emerging practice by the NSP.										
Picture Exchange Communication	Picture Exchange Communication System was identified as an emerging practice by the NSP.										
Extinction	Extinction (Reductive Package) was identified as an emerging practice by the NSP.										

Strength of Evidence Classification System

Established	Emerging	Unestablished	Ineffective/Harmful
• Several published, peer-reviewed studies • Beneficial treatment effects for a specific target • Scientific Merit Rating Scale (SMRS) scores of 3,4, or 5	• Few published, peer-reviewed studies • Beneficial treatment effects reported for one variable • SMRS score of 2	• May or may not be based on research • Based on very poorly controlled studies • SMRS 1 or 0 • Ineffective, unknown, or adverse treatments	• Several published, peer-reviewed studies • SMRS scores of 3 • NO beneficial treatment effects OR • Adverse treatment effects (Harmful)



National Autism Standards ranking = Established!

Arranging the Environment

- Create a supportive environment to increase learning and decrease stress and problem behaviors
  - Remember
    Visual Supports!

Physical organization of space and materials

Schedules & Choices

iGet – my schedules at school

Implementing Pre-Activity Interventions (Priming)

- Providing ample notice prior to an upcoming activity (visual and verbal!)
- Reviewing an assignment before class starts
- Providing information about schedule changes
- Using activity schedules

Give them a "heads up"

Question: How do you teach an individual with ASD to navigate a new skill?

Answer: Task Analysis

National Autism Standards ranking = Established!

The cafeteria/bus stop/family gathering (etc.) is sensory overload . . . So intervene BEFORE!

- To teach them how to navigate a new skill, a teacher/clinician/parent would need to:
  - Figure out the best task analysis for the skill
  - Identify how to teach the skill
  - Think about chaining it all together
  - Prompt system to help when first teaching the skill and when it breaks down

How it works?

- Task analysis is the process of taking a chained task and breaking it up into teachable components or a set of discrete steps.
- Examples of skills that can be taught using a task analysis:
  - using a drink machine,
  - purchasing food at a fast food restaurant,
  - progressing through an algebraic equation, and
  - participating in a literacy lesson.

Make sure you determine the critical steps & field test your steps!

Equally as important though. . .

What is your favorite high school memory?

Social Events!

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Social skills and EBP?

- More extensive research is needed beyond preschool & elementary years
- Eclectic approaches
- Variety of practitioners
- Limited practice opportunities
- Limited generalizability

National Autism Standards ranking = Social Stories are Established!

Social Skills Training may include:

1. Peer De-mystification!
2. Teach the unwritten rules
   – the "Hidden Curriculum"
3. A structured and systematic "rule" system applied to abstract and unstructured social scenarios
   - Task analysis

4. Opportunities to practice with group members and typical peers
5. Personalized Social Stories

"The Hidden Curriculum"

Brenda Smith Myles

"The set of unwritten rules that no one has been directly taught, but everyone knows. Violation of these rules can make an individual a social outcast."

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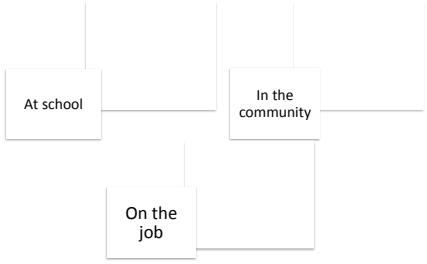
There is a hidden curriculum . . .



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Ever been in a boy's bathroom?

- What is the hidden curriculum at the urinal?


Credit: Brenda Smith Myles

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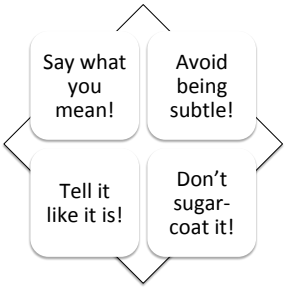
Context, Context, Context!

Fist bump is out!

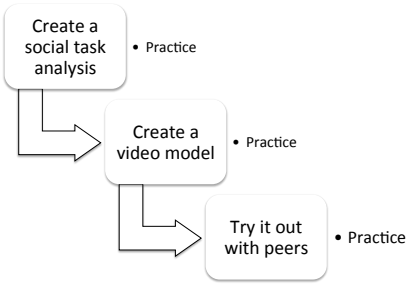




To teach the hidden curriculum . . .



Tips for teaching social skills:



Let me tell you a story …

- Once upon a time
  - 3 teenagers
  - Two therapists
  - Lots of Social Skills "training"
    - Social Stories
    - Social Thinking
    - Social Task Analysis
    - Etc. etc. etc . . .

Acquisition vs. Performance deficits

(Bellini, 2008)

Skill Acquisition Deficit	Performance Deficit

• Absence of a specific skill or behavior
• Child or adolescent needs to be taught the skill or behavior
	• Skill or behavior is present, but not displayed
	• Child or adolescent needs to be supported; factor impeding implementation needs to be addressed
	  • Motivation
	  • Anxiety
	  • Sensory sensitivities, etc.

More answers!

Biological tests vs. observations

What's next for Autism?

Targeted interventions

Adult transition supports

Any Questions?

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